

Topics covered in the parent resource *Caring Decisions*

(available at <http://www.rch.org.au/caringdecisions/>)

- Introduction
 - How common are decisions about life support for children?
 - Why should I read this handbook?
 - Is this handbook relevant for my child?
 - How should I read this book?
 - Why am I being asked these questions? It is not given to me to decide about life
 - Starting a conversation with your child's doctors
 - 'The bigger picture'
 - There is too much to think about...
 - I don't understand...
 - Support at a stressful time
 - Terms used in this handbook
- How do parents think about end of life decisions
- Life support treatment
 - What is life support treatment?
 - Are there different types of life-support treatment?
- Comfort treatment and palliative care
 - What is comfort treatment and palliative care?
 - Is palliative care just for children who are dying?
 - Can a child have comfort treatment and life support treatment?
- Stopping life support
 - Why would doctors want to stop life support treatments for my child?
 - Are there different reasons for stopping or not starting life support treatment?
 - Is it legal to stop or not start life support treatment?
 - Is stopping treatment euthanasia?
 - What is futile medical treatment?
 - Futile treatment and the dying process
 - Questions you could ask
- Stopping and not-starting
 - Is there a difference between stopping treatment and not starting treatment?
 - What if I still feel uncomfortable stopping life support treatment for my child?
 - What is a 'trial of life support treatment'?
 - Questions that you could ask your child's doctors about treatment:
- Different types of treatment
 - Are decisions different for different life support treatments?
 - Is it OK to stop some life support treatments but continue others?
 - What is a DNAR or AND order?
 - If I agree to a DNAR order for my child will other people know?

- What will other people think of me if I agree to a DNAR for my child?
- If I agree to a DNAR will other treatment stop?
- What if I change my mind?
- What if I decide that I want doctors and nurses to provide CPR for my child?
- I want everything to be done
- Is it OK to stop artificial feeding?
- Is it legal to stop artificial feeding?
- Doing what is best
 - What is the right thing to do?
 - How do we work out what would be best?
 - Should I ask my child?
 - What if my child doesn't want life support treatment?
- Quality of Life
 - What is 'Quality of Life'?
 - Is it appropriate to use quality of life when making decisions for children?
 - Are all 'quality of life' decisions the same?
 - Are 'quality of life' decisions different in children?
 - What about the 'sanctity of life' approach? Isn't life sacred?
 - Is it discriminatory to stop life support treatment based on 'quality of life'?
 - Is quality of life a 'personal' decision?
 - Questions you could ask your doctor
- Uncertainty
 - Can the doctors be certain about what will happen for my child?
 - Questions you could ask your doctor about uncertainty
 - Ways to think about uncertainty
 - Is there a rush to make a decision? Do I need to decide now?
 - I have read about a new treatment/test on the internet...
- Who decides about life support?
 - Who makes the final decision about life support treatment?
 - What does shared decision-making mean?
 - Questions you might like to ask your doctor
 - Phrases that may be helpful
 - What if I don't want to decide?
 - Do parents need to consent to stopping treatment?
 - What would you do doctor?
- Disagreement
 - What should I do if the doctors don't agree about life support?
 - What should I do if I don't agree with my child's doctors about life support?
 - What should I do if my partner and I do not agree about life support treatment?
 - What should I do if others in my family do not agree about life support treatment?
- Religion, culture and life support
 - Is it against my religion to stop life support?
 - Is it playing God to stop life support?

- What about the sanctity of life?
- I don't want to stop life support because I am waiting for a miracle
- Can I talk to my doctor about my cultural or religious beliefs?
- Can I ask doctors to speak to my elder or religious advisor?
- What do different religions say about stopping life support?
- After a decision
 - We have decided to continue life support. What will happen now?
 - We have decided to stop or not start life support. What will happen now?
 - What happens after a breathing tube is removed?
 - If my child has morphine, will it stop him/her breathing?
 - How long do we have?
 - What about organ or tissue donation?
 - What do I do about organising a funeral?
- Taboo questions
 - What if I had... If only I had...?
 - Is it bad to wish for my child to die?
 - Can't the doctors give my child something to put them out of their misery?
 - Do doctors want to stop life support for my child because it costs too much?
 - Is stopping life-support treatment giving up on my child?
 - Is there no hope?
 - The doctors cannot be right. They must have made a mistake.
 - If I agree to stop life support, will people think I am a bad parent?
 - Will we be abandoned?
 - Will I be letting the doctors down if I agree to stopping or not starting life support?
 - What about the rest of my family and their quality of life?
 - I am afraid that I won't be able to cope if...
 - 'Did I make the right decision?' Will I be able to live with myself?
- What to tell other people
 - Should I say anything?
 - What do I tell other people about life support?
 - What do I tell my other children?
- Further information